University of Alberta

Shifting to conscious control – psychosocial and dietary management of anorexia by patients with advanced cancer

by

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DEDICATION

To Enid Paula Shragge, RN (1951-1998)

Who once observed that no one in her son's high school graduating class chose to study nursing. May this work help remedy that deficiency.

ABSTRACT

Although anorexia (loss of appetite) is one of the commonest symptoms of advanced cancer, surprisingly little is known about how patients experience or adapt to it. Grounded theory method was used to investigate the basic social psychological process employed by patients to compensate for anorexia and manage its emotional and social consequences. By *shifting to conscious control* over their intake of food, participants (n=9) retained the ability to eat with simple appetite loss. Whilst anorexia was not in itself necessarily distressful to participants, its logical, long term consequences (e.g., weakness and starvation) were. Acknowledgement of these deleterious outcomes motivated participants to continue attempting to eat. Although a number of symptoms contributed to declining intake of food, nausea or the anticipation of emesis was most commonly named as the ultimate barrier to eating. The implications of *shifting to conscious control* for the development of innovative clinical interventions are discussed.

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Finally, this study never would have been possible were it not for the willingness of seven men and two women, all of whom suffered from an incurable disease, to volunteer hours of their lives over several days to speak to a complete stranger about their experiences with food, eating, appetite, cancer, death, dying and life. I could offer them nothing but a non-judgmental ear and the pledge to utilise their gift so that one day others could benefit. It is my greatest hope that the work contained in this volume fulfils my promise and honours their contribution to science. *Alev hashalom.*

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Chapter 1: Introduction

Through its suppression of caloric intake, loss of appetite is a major contributor to the weight loss and emaciation that are hallmarks of incurable malignant disease. In fact, anorexia (literally, 'loss of desire') is one of the commonest symptoms experienced by patients receiving palliative care for metastatic, recurrent or refractory cancer (collectively: "advanced cancer"). Walsh et al.,[1] for example, observed that 66% of patients (n=973) reported loss of appetite upon referral to a palliative care programme; it was the third most frequently registered of the 38 symptoms evaluated. Another study performed at the same treatment centre, Sarhill et al.[2] found anorexia to be the second most widespread of 16 "gastrointestinal" conditions; eighty-one percent of patients (n=352) offered that they had experienced this symptom.

Anorexia has been identified as an independent prognosticator of survival for patients with advanced malignant disease [3-6]; furthermore, Andreyev et al.[7] have hypothesised that patients who have experienced weight loss prior to a course of systemic treatment will receive less overall chemotherapy – with potentially deadly consequences.

Loss of appetite can be differentiated into two categories based on aetiology.[8] Primary anorexia indicates appetite loss that is thought – based on animal models – to be linked to the breakdown of one or more of the neurohormonal signalling pathways that regulate appetite. Pro-inflammatory mediators are believed to be responsible for these dysfunctions [9-12]; however, in humans, direct evidence to support such hypotheses is fundamentally absent.[10] Primary anorexia, therefore, remains a poorly understood[9, 10] and poorly managed[13] condition of advanced cancer. Secondary anorexia, on the other hand, refers to those factors that may directly or indirectly contribute to a reduction in caloric intake. These myriad symptoms and conditions are independent of appetite signalling and may be either of a psychosocial (e.g., depression, alternative diets, indigence) or physiological nature (e.g., chemosensory alterations, stomatitis, pain, dyspnoea, bowel obstruction).[8]

The relative contributions of primary and secondary anorexia to caloric intake decline amongst patients with advanced cancer are unknown. In animal models,

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The reader is reminded that this chapter was written in spring of 2004 as the "Literature Review and Background" of this study's protocol. Aside from changes to the citation format, the material is unaltered from the original.

caloric intake is known to decline progressively, commensurate with increasing tumour burden,[14] whereas in humans total caloric intake and disease progression appear to be unrelated; data from the nutritional database of the Alberta Cancer Board's Palliative Care Research Initiative clearly indicate that caloric intake does not correlate with proximity to death. Sarhill et al.[2] have observed that a small but noteworthy subset of patients who reported anorexia nevertheless maintained a normal or higher caloric intake. In other words, some patients were able to psychologically override the mechanisms that regulate their appetite. This suggests that amongst advanced cancer patients variables other than disease progression, (e.g., psychosocial factors) may play a role in determining both the manifestations and consequences of anorexia (e.g., what, when, where, why, how much, with whom, and for whom patients will eat).

Whilst the majority of the individual contributors to secondary anorexia are effectively tractable, clinically meaningful attenuation (or reversal) of neurohormonal appetite loss has proven notoriously difficult.[13, 15] Treatment of appetite regulation dysfunction is often seen as an element of cachexia-anorexia pharmacotherapy. In this emergent therapeutic paradigm, a wide array of drugs is exploited to target the physiological mechanisms ultimately responsible for patient weight loss and emaciation, e.g., appetite signalling, muscle and adipose catabolism, systemic inflammation (see reviews by Davis et al.,[10] Macdonald et al.,[15] Fearon & Moses,[16] and Inui[12]). Despite recent advances in research, the biochemical nature of cancer-associated anorexia and hypermetabolism remains poorly elucidated[10]; furthermore, the orexigenic agents typically used to treat appetite loss (e.g., megestrol acetate and dexamethasone) tend to produce significant results in only a sub-set of 'responders'.[17] This problem is exacerbated in clinical practice by the reality that not all patients are offered appetite stimulants, and some, due to side-effects or cost, may either refuse or discontinue them even when they are prescribed. Ultimately, the profound challenges associated with the treatment of appetite loss necessitate the use of other strategies, in particular nutritional counselling, to help patients manage anorexia.

Unfortunately, as Brown & Radke[18] have noted, there is a distinct possibility that "traditional nutritional assessment guidelines lack clinical utility, specificity, or

sensitivity in the cancer population (p. 552); furthermore, no standardised group of measurable outcomes has been developed by which the efficacy of nutritional counselling of cancer patients may be evaluated. A great many of the commonest endpoints such as improved nutrition (e.g., increased caloric intake and protein consumption), weight gain, decreased morbidity, enhanced quality of life, prolonged survival,[18] increased physical activity[19] or greater enjoyment of food have a distinct psychosocial component. It has been found, however, that the most frequently recommended interventions attend to the problem of poor caloric intake in isolation, i.e., patients are simply counselled to consume more calories and/or protein [18]; consequently, the psychosocial dimensions of appetite loss and other nutrition-associated symptoms are virtually ignored.

The very fact that patients seek treatment for eating related disorders logically implies that these symptoms are aggravating to patients; however, the manifestations of their problematic nature are very poorly described.[20] Indeed, very few studies have endeavoured to craft a conceptual understanding of how *patients* experience and manage loss of appetite. This gap in the knowledge base represents a significant barrier to the delivery of effective and meaningful nutritional interventions.[20]

Dixon et al.[21] have proposed that families experience a spiralling "syndrome of psychosocial interactions" (p. 29) as a consequence of the cancer sufferer's declining appetite and increasingly frequent food refusal. Such a condition serves to underscore the patient's deterioration and sound the approach of death. Qualitative studies published by Holden,[22] Meares,[23] and McClement et al.[24] have begun to expand and describe in some detail the process hypothesised by Dixon et al.[21]

Holden[22] queried 14 patient-caregiver dyads to ascertain how each participant viewed and responded to the patient's anorexia. The author concluded that there was a tremendous exertion of physical and emotional energy on the part of caregivers in order "to cope with a problem to which patients were quite resigned" (p. 83). Although sadness was associated with lost opportunities for social interactions due to patients' inability to take meals, eating was seen by nearly all participants as contributing to patient well-being. Holden[22] concluded that the emotional reaction to cancer-associated anorexia was the same as that of any "loss"; consequently, health

care interventions aimed at palliating anorexia ought to recognise the psychosocial component of appetite loss in order to have therapeutic efficacy.

Taking a phenomenological approach, Meares[23] examined the meaning of anorexia and gradual intake cessation from the perspective of 12 primary caregivers of malignancy sufferers who had received palliative homecare. Patients were reported to have eaten to assuage caregiver anxiety and to have pleased their families, whilst caregivers exerted relational pressure, e.g., nagging and begging, in order to promote intake.

McClement et al.[24] attempted to gain a conceptual understanding of the ways in which family members and/or caregivers responded to the nutritional care of advanced cancer sufferers living in a Western Canadian hospice. Directed by the Grounded Theory methodology (see below), the authors identified the sub-processes of "fighting back", "letting nature take its course" and "waffling". These three themes were components of "doing what's best": the basic social process used by family members to "ensure that the nutritional care they deemed optimal in order to achieve their desired goal was received by the patient" (p. 739). Patients whose family members utilised "fighting back" behaviours reacted with anger and distress – to the point of being force-fed in some instances. Those patients whose caregivers allowed nature to take its course reported appreciation at not being coerced into eating or being made to feel guilty because of their low caloric intake.

The importance to cancer patients of appetite and its loss cannot be over-emphasised.[25] The impact of enhanced nutrition on weight gain, quality of life and physical activity[19] amongst those suffering from incurable disease can be extraordinary. Anorexia may hasten patient death and undermine tolerance to treatment. Just as significantly, it has the ability to place tremendous stress on patient-family relationships. Because orexigenic agents are effective and appropriate for only some patients, other clinical interventions must be used to address loss of appetite. To have meaningful impact, nutritional counselling must be responsive to the psychosocial consequences of anorexia; however, current assessment guidelines do not adequately address this crucial requirement. At the moment, little is known about how patients experience appetite loss or manage their eating as a result of anorexia. A

conceptual understanding of these essential characteristics is essential so that they may be integrated into the development and delivery of sound nutritional interventions.

The current project seeks to move beyond the family/caregiver centred approach employed by Holden,[22] Meares,[23] and McClement et al.[24] and intensively explore the experience of anorexia through the patients' lens. Holden[22] and McClement et al.,[24] in particular, have provided extremely important – but tantalisingly brief – glimpses into the world of appetite loss in advanced malignant disease; however, a model through which primary and secondary anorexia may be conceptualised has yet to be developed that is *grounded in the patient experience*. The primary objective of this study is, therefore, the creation of a theoretical framework that integrates the strategies used by advanced cancer patients in the management of the nutritional and psychosocial consequences anorexia. In the future, it is hoped that this process model will aid clinicians in providing efficacious interventions that will help alleviate the deleterious nutritional effects of malignant disease.

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Chapter 2: Manuscript 1 – Literature Review

The management of anorexia by patients with advanced cancer: a critical review of the literature

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Key words: anorexia; neoplasms; appetite; adaptation, psychological; palliative care; qualitative research

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Introduction

Through its suppression of caloric intake, loss of appetite is a major contributor to the weight loss and emaciation that are hallmarks of incurable malignant disease.[1] Anorexia (literally, 'loss of desire') is one of the commonest symptoms experienced by patients receiving palliative care for advanced cancer[2-4] and has been identified as an independent prognosticator of decreased survival.[3, 5-7]

It is unclear how many patients are being treated for anorexia;[8] furthermore, the proportion for whom appetite loss and declining intake of food are distressing is similarly opaque;[9] however, the fact that some patients seek treatment for anorexia logically implies that this symptom is at least somewhat aggravating and deserving of clinical attention.

Anorexia, like cachexia, the syndrome of skeletal muscle wasting and abnormal carbohydrate and fat metabolism that often accompanies it, is a poorly managed condition in palliative care.[10] This is due, in part, to the marginal efficacy of the orexigenic agents most frequently prescribed to attenuate or reverse appetite loss. The appetite stimulating effects of corticosteroids tend to dissipate after four weeks,[1] whilst progestins, such as megestrol acetate, provide meaningful relief for only a minority of patients[11-13] and are not indicated in very advanced disease.[14] Other barriers to optimal management include the use of inappropriate nutritional assessment guidelines and interventions,[15] as well as a poor understanding by clinicians of the psychosocial problems associated with anorexia and weight loss.[9]

Even when possible, the reversal of anorexia has been shown to have little impact on the course of the cancer trajectory[1]; nevertheless, it has been suggested that therapies to improve appetite are important irrespective of their impact on morbidity or survival.[11, 16] The modest effectiveness of the standard treatments for appetite loss, as well as their limited potential to increase objectively measured quantity of life,[11] militate for responsive interventions that assist patients and caregivers to cope with the social and psychological consequences of anorexia.[17]

In order to lay the ground work for the development of such interventions, this report presents a critical review of the scholarly literature on the experience of

advanced cancer patients with anorexia. The main objective is to characterise the strategies used by patients to manage this symptom.

Method

The material evaluated in this report was identified through a methodical search of four electronic databases accessed from the OVID platform: MEDLINE, CINAHL, PsycINFO and EMBASE. Based on our previous experience with the published work in this area, a broad search strategy was developed that encompassed two distinct areas: nutritional issues in advanced cancer and/or palliative care, and the impact of nutritional factors on quality of life in advanced cancer treatment.

Beginning with MEDLINE, key words and Medical Subject Headings (MeSH) within the ambit of these broad topics were identified, pooled as three thematic unions ("cancer", "nutrition" and "palliative care/quality of life"), and applied to create a single, comprehensive search intersection. The search terms were then tailored to fit the indexing schema of the other databases.[18]

Inclusion/Exclusion Criteria

Papers were considered for evaluation if they were published in peer-reviewed, English language periodicals that were available through the NEOS Library Consortium, Canada Institute for Scientific and Technical Information document retrieval system or interlibrary loan. They were required to have

- presented the results of clinical research (qualitative or quantitative); or reviews of the scholarly literature;
- involved mainly patients suffering from advanced cancer; and
- explored the effect of anorexia, intake decline or cessation, malnutrition or weight loss on the lived experience of patients, caregivers, or other family members

It was recognised from the outset that the literature relevant to the stated objectives would be limited;[9] accordingly, exceptions to the above criteria were made for several non-peer-reviewed papers (e.g., clinical guidelines and short articles) and books that usefully contributed to the analysis. Clinical research and literature reviews primarily related to the effect of appetite stimulants and aggressive nutritional support (i.e., tube-feeding and parenteral alimentation) were excluded, as

were unpublished dissertations, papers involving early or mixed stage cohorts of patients and editorials.

Appraisal and Supplementary Searches

The results of the four database searches were exported into RefWorks (web-based bibliographic management software) and combined. Articles selected for final critical appraisal were subjected to a three-stage review process (with increasing specificity), based on the above inclusion/exclusion criteria. The titles of all papers were initially assessed, and those deemed irrelevant or beyond the scope of our objectives were excluded. Following this, the abstracts of the remaining articles were retrieved and studied. The full text of those papers that could not be confidently eliminated based on their abstract were retrieved and assessed.[19]

It was presupposed that the search strategy applied to the four databases would be bound to exclude a number of pertinent and instructive papers. To remedy this deficiency, a number of supplementary searching techniques were employed. First, the bibliographies of all articles that were appraised were consulted for potentially germane references. Second, a number of key papers included in the final analysis were subjected to a Web of Science cited reference search. Third, authors of highly significant or seminal articles were searched in by name to identify any additional publications of relevance. Fourth, based on our experience and expertise, other papers of potential interest were retrieved and reviewed.

Definitions

Advanced Cancer

The scholarly literature is bereft of a single, clearly delimited, widely employed definition of "advanced cancer". Cancer has been deemed "advanced" when it was metastatic,[2, 20] metastatic or recurrent,[21] metastatic or locally diffuse,[22] or treated with palliative care.[4, 23-26] So as to integrate the experience of as wide a spectrum of patients as possible in this analysis, advanced cancer is broadly defined as malignant disease that is fundamentally incurable, likely to be lethal, but not necessarily impervious to life-prolonging therapies.

Anorexia and Reduced Caloric Intake

In the strictest sense, anorexia means loss of hunger or the desire to eat[27] as subjectively determined by patients.[28] Although, the prevalence of anorexia has been frequently reported in a binary manner,[2, 25, 29] inappetence is more usefully understood as falling along a continuum.[3, 4, 26, 30] Minimum thresholds of intensity and duration have, however, yet to been established.[9] Cancer associated anorexia may be categorised as either primary or secondary based on aetiology.[31] Primary anorexia is a poorly understood[8, 16] and frequently neglected[32] condition of advanced cancer. It is believed, based on animal models, to be linked to dysfunction in one or more of the "hypothalamic, neuronal signalling pathways" that regulate desire for food and satiety.[32] Pro-inflammatory cytokines are believed to be at least partially responsible for these dysfunctions[8, 16, 32, 33]. In humans, however, little direct evidence exists to support these hypotheses.[8] Secondary anorexia refers to those factors that aggravate primary anorexia's effect on caloric intake and absorption, in particular those symptoms that effectively act as barriers to caloric intake (e.g., food intolerances, altered chemosensory perception, nausea, xerostomia, constipation, dysphagia).[31]

Whilst several authors have defined anorexia as comprising appetite loss and reduced caloric intake,[9, 15] these two are in fact independent clinical conditions and should not be conflated.[16] Patients with little desire to eat may eat normal amounts[2] or those appropriate for their mass and activity level.[16] Reduced caloric intake is properly envisaged as a consequence of anorexia, whilst malnutrition and weight loss follow from the former – albeit, these last two conditions may occur independently of caloric intake.[2, 34]

Results

The social-psychological imperative to seek food

Hughes and Neal[35] suggest that eating behaviour in humans is reflective of a biological imperative to seek food; however, anorectic patients are deprived of the spontaneous and previously taken for granted impulse to eat. Eating without an appetite becomes at best challenging and at worst impossible.[36-40] Patients with anorexia must, therefore, make a choice to eat, because the failure of the biological

imperative to seek food renders *not* eating the default condition. In other words, appetite loss and other symptomatic barriers to caloric intake undermine the biological imperative in patients with advanced malignant disease. Despite this, much evidence exists that anorectic patients at the very least attempt to maintain some intake of food.[17, 37, 39-41]

Consequent of the self-evident relationship between intake cessation and starvation,[39] the disrupted biological imperative appears to be compensated for by social and psychological factors that motivate continued eating. When considered collectively, these factors represent a cognitively generated impetus to eat that prevents anorexia from becoming an absolute barrier to eating[42] – if, perhaps, only temporarily.[43] As such, it is a fundamental cognitive strategy used in the management of appetite loss (i.e., the employment of adaptations that attempt to minimise the deleterious effects of this symptom on physical and psychosocial wellbeing).

Support for the existence of a social-psychological imperative to seek food may be inferred from studies that demonstrate the desire or ability of patients to eat despite minimal or completely absent appetites. McCann et al.[41] observed 32 cognitively intact hospice patients, 31 of whom had cancer, from the time of admission to death. Levels of thirst, xerostomia and hunger were assessed several times daily by patient self-report, and the consumption of food and drink was monitored for physiological sufficiency. Although 63% of patients (n = 20) expressed no sensation of hunger upon admission, all but two of this group managed a "reduced consumption" of food, indicating an intake of "less than 25% of normal solid and liquid consumption" (p. 1265). It may be assumed that one or more motivational factors stronger than, for instance, boredom or habit, impelled the participants studied by McCann et al.[41] to continue eating, notwithstanding their want of hunger.

The ability to support a caloric intake despite having little or no appetite may be contingent upon successful palliation of the many symptomatic barriers that are reported by patients to accompany appetite loss and contribute to declining intake of food.[37, 39, 40, 44] Feuz and Rapin[42] observed 116 elderly, institutionalised patients with incurable cancer. They note that 92% of their subjects ate until their respective day of death. The control of pain and the side effects of analgesics (e.g., nausea, emesis,

heartburn and constipation) were found to have been instrumental in the ability of patients to eat with minimal or no appetite. The authors conclude that simple appetite loss was not necessarily an insurmountable obstacle to eating.

Several recent, qualitative studies suggest that anorectic patients with advanced disease generally wish to maintain an intake of food and continually motivate themselves to do so; furthermore, patients appear to place tremendous value on endeavouring to eat, irrespective of success.[37, 39, 40] This is not to say, however, that anorectic patients never consciously decide to cease eating. Hopkinson and Corner[37] interviewed 30 palliative cancer patients along with a number their caregivers and homecare nurses in the south of England. They describe several patients "making a choice not to eat" (p. 15) as one form of dietary manipulation in order to assert control over their destiny or restrict the progression of the tumour.[37] This finding is congruous with research that suggests some cancer patients choose to hasten death by intake cessation.[45] Aphagia is reported not to cause suffering and, in fact, may forestall physical distress attendant to forced eating.[41]

If persistent eating without appetite were indicative of a powerful, cognitively generated impetus, the rational antecedents of this imperative remain poorly elucidated. In an interview study of 13 advanced cancer patients and 11 of their family members, Orrevall et al.[39] report that the general importance of a sufficient intake of food was well recognised by patients. More specifically, Hopkinson and Corner[37] describe that the maintenance of health and wellbeing appeared to play a role in motivating patients to eat.

Souter[40] interviewed seven cancer patient-caregiver dyads in Cornwall, who were supported by a palliative homecare service, about their experiences with appetite loss. Under the theme of "facing uncertainty and death" the author reports that all participants appreciated the relationship (either direct or indirect) between eating and the maintenance of strength and health; however, only one patient openly acknowledged death as the ultimate consequence of inadequate caloric intake. The author conjectures that the reticence of participant to discuss the causal relationship between anorexia and death (by starvation) reflected a form of coping that avoided the evocation of "overwhelming anguish" (p. 528). This finding is somewhat

inconsistent with those of several other, non-British studies in which the relationships between adequate caloric intake and survival, and cessation and death by starvation were more frequently acknowledged by patients[39] and caregivers[29, 38, 39, 44]

Adapting to limited capabilities

Hopkinson and Corner[37] conclude that active management of anorexia was triggered when a disconnect developed between the expectations of eating held by patients and the reality of their increasing inability to fulfil those expectations. Some patients simply accepted the inability to eat, and exerted no conscious effort to manage these changes. Others engaged in a variety of compensatory activities. Collectively labelled "self action", these included seeking assistance, manipulating dietary intake, relying on supplements and avoiding social eating.[37] Brief reports of the avoidance of social eating,[40] manipulation of dietary intake[40] and reliance on supplements[39] appear elsewhere in the research literature. The manipulation of food (e.g., presenting favourite foods, leaving food in conspicuous or accessible places, adjusting portion sizes) has been noted as a strategy used by caregivers to induce patients to eat.[38, 39, 44, 46]

Parenthetically, the concept of patients "forcing" themselves to eat remains a nebulous one. The actions of patients who carry on eating whilst suffering nausea sufficient to induce emesis,[39] as well as those who eat in order to relieve the worry of family members only to vomit as a consequence.[44] may be interpreted as forcing. Hopkinson and Corner[37] note that several patients claimed to be forced into eating by family members – albeit, whether the former were physically force fed[38, 44, 46, 47] is unclear. Patients were also observed by Souter[40] to have forced down food. In the next sentence, however, this author goes on to assert that "Despite their desire to eat more they were unable to do so however hard they tried" (p. 529). These two statements are somewhat contradictory and raise several questions: can anorectic patients eat without forcing? Under what conditions does eating become forced as opposed to merely difficult? What factors facilitate and thwart forced eating for those with anorexia? At what point does forcing become impossible?

Seeking Assistance

Although the strategies employed by patients to compensate for anorexia have not been widely studied, the experience of seeking and obtaining professional assistance for eating problems has received greater attention. The patients interviewed by Hopkinson and Corner[37] reported that the advice proffered by healthcare professionals was often disappointing, in part due to its lack of personalisation. This finding is not altogether surprising when it is considered that these patients also expected to obtain little utility from the professional guidance sought. The family members interviewed by Orrevall et al.[39] articulated a comparable impression of the support provided by dieticians. They felt that the advice was infrequently novel or little more than common sense; moreover, it was judged to have been too general and insufficiently tailored to fit the conditions faced by individual patients. The role of dieticians was seen as having been both marginal and ad hoc, a view that accords with observations made by McClement et al.[44] on one Canadian palliative care ward.

Survivors of peripheral blood stem cell transplantation and caregivers of patients who died of haematologic malignancies expressed mixed feelings about the role played by dieticians and physicians in the treatment of anorexia.[36] The advice provided by the former was often appreciated and believed appropriate, but in many instances it was felt to have been uncreative, impersonal and, at times, delivered imperiously. The role played by physicians was seen as having been similarly important; however, bereaved family members recalled incidents in which doctors displayed a distressing lack of sympathy or even failed to recognise a patient's anorexia. The participants interviewed by Orrevall et al.[39] reported similar negative experiences with physicians. They noted that treatment of the tumour occupied the lion's share of both the doctor's interest and the appointment duration.

The attitude and approach of physicians discussed above raise the question whether there is a sigma attached to anorexia and other nutritional issues? The nurses interviewed by Hopkinson and Corner[37]believed that the issue of appetite loss was wisely circumvented in order to avoid exacerbating the injurious psychosocial effects of the (futile) situation. This finding compliments the results of a separate analysis of these interviews, which revealed the existence of a taboo around weight loss.[48]

Although 60% of the patients in the sample (n = 18) had been weighed at least once whilst enrolled in the palliative care programme, only two could ever recall having discussed their declining weight with their homecare nurses. The nurses, in turn, articulated that they avoided raising the subject because they believed there was little they could do to effect an improvement. They also feared exacerbating emotional discord and social tensions.

The weight loss taboo appears to exist amongst dieticians and physicians as well. The latter have been reported not to enquire about weight loss and, in some cases, ignored the issue even when they were aware of it.[39] *Nutritional Care of the Terminally Ill*, a prominent American text on dietetics in palliative care, fosters the putative stigmatisation of weight loss:

> Indeed, asking about weight, a common and appropriate question asked in nutritional assessments of acute care patients, may not be appropriate with the terminally ill patient. It is only appropriate when the patient expressed sadness about weight loss… and the change in the patients' views of their bodies[49] (p. 124).

Although the approach to monitoring weight loss suggested by the above passage is unlikely to be unique amongst North American healthcare professionals, the clinical research suggestive of the existence of weight loss and anorexia taboos was performed entirely in Europe.[37, 39, 48] Ultimately, more research is required to determine to what degree these issues are stigmatised by oncology and palliative care professionals, and whether nutritional issues related to advanced malignant disease are approached differently in Europe and North America. Trans-Atlantic cultural differences may impact the attitudes of European and American clinicians toward these issues, as well as influence the form of support offered to patients.[9]

Coming to terms with the loss

The negative impact of weight loss and malnutrition on objectively measured quality of life,[20, 22, 50-52] treatment response,[20, 53] survival,[5, 20, 54, 55] and cancer-related mortality,[56] is well recognised in the scholarly literature. More important, patients themselves appear to acknowledge anorexia's grave, long-term implications for

health and survival.[39] It is somewhat surprising, then, that appetite loss has been found to be more problematic for caregivers than patients, especially in latter stages of the disease trajectory.[9] Anorexia tends to cause considerable anxiety[57] or distress[58] for caregivers, as well as social and relational discord within family units.[17, 37, 38, 39, 40, 43, 44] On the other hand, British patients have been reported to suffer significantly lower levels of anxiety than their family members[57] as well as generally low absolute levels of distress as a result of appetite loss[59] – albeit, Chinese patients do not appear as tolerant of anorexia, suffering considerable distress from this symptom in the last week of life.[60]

Acceptance of or resignation to the limitations on their eating capabilities appears to allow patients to avoid much of the psychological trauma related to anorexia suffered by their caregivers.[17, 37, 40] Any psychological suffering that patients do experience appears to be largely indirect, attributable to the strain placed on the caregiver-patient relationship by inability of the former to accept the eating limitations faced by the latter.

Holden[61] interviewed 14 patient-caregiver dyads in the United States. This author was the first to suggest that patients and caregivers display disparate levels of acceptance to anorexia, and that the latter often expend a 'tremendous amounts of emotional and physical energy attempting to cope with a problem to which patients were quite resigned (p. 83). Although caregivers would often emphasise the negative characteristics of patients' intakes of food, the patients spoke more positively about their diets and shifted the focus of their narratives away from the quantity of food consumed. As this author and McClement et al.[44] report, anorexia was felt by patients to be equally or less important than other symptoms. Souter[40] suggests that accepting the limitations on their eating capabilities, "meant that patients were not distressed constantly by their loss of appetite, [because] they knew they were doing all they could" (p. 530). Indeed, four of the seven patients interviewed by Souter[40] explained that what concerned them most about their anorexia was the worry it caused their caregivers. Hopkinson and Corner[37] propose that acceptance of eating changes enabled patients who were approaching death to live free from guilt and self-blame.

Much of the anger and frustration expressed by caregivers who struggle against patient appetite loss and poor caloric intake is speculated to follow from their inability to achieve the goal of feeding patients. Meares,[43] interviewed 12 bereaved caregivers of advanced cancer patients, and suggests that individual caregiver responses to intake cessation were a function of, *inter alia*, the level of responsibility assumed to facilitate eating by the patient.[44] Hopkinson and Corner[37] propose that the acceptance and enjoyment of food, which represented effective care giving, were rewards sought by caregivers from patients. Because anorexia interfered with the provision of these rewards, familial relationships suffered. In addition, failure to meet expectations regarding eating that patients perceived were held for them by caregivers led to guilt, inadequacy and self-recrimination.

Souter[40] proposes that "The view that appetite loss is a cause rather than a symptom of dying appears commonplace in society" (p. 532). Whilst the diffuseness of this myth is unclear, it appears that some family members aggressively resist patient anorexia out of the belief that reduced caloric intake, rather than progressive disease, is the primary cause of their relative's physical decline. As a consequence, family members infer that nutritional repletion will stop or reverse the deterioration.[38, 44] Although relational pressure has been reported to increase the intake of food by patients,[37] it has been shown to have the opposite effect, which led to tension.[37, 39] Familial stress has been related to excessive vigilance and control exercised by caregivers over patients' diets.[38, 39, 44] Such strategies are classified by McClement et al.[44] as "fighting back" behaviours and are believed to have contributed to feelings of emotional distress in patients. These, in turn, provoked patient withdrawal and forced eating, the last of which was feared by healthcare professionals to expose patients to physical danger.

Family members who McClement et al.[38] label as "letting nature take its course," illustrate the importance of caregiver acceptance to the successful management of anorexia by patients. Several studies have confirmed that patients are often appreciative of their caregivers' efforts to help them eat;[39, 61] however, it seems clear that patients wish to control their intake of food[61] and have caregivers understand and accept the often insurmountable barriers standing in the way of eating.[40]

Conclusion

Few studies have examined the adaptive strategies used by advanced cancer patients to compensate for appetite loss and manage its emotional and social consequences. The present review suggests that patients with little or no spontaneous desire to eat come to rely on a social-psychological imperative to seek food. Whilst many patients (and their caregivers) often seek assistance from healthcare professionals, the proffered advice is not always seen as being especially useful or delivered in an appropriate manner. Based on a single study into the impact of both appetite and weight loss in advanced cancer patients, there is evidence to suggest that some palliative care clinicians consider these symptoms to be taboo subjects. This may be related primarily to the difficulties associated with reversing these losses.[37, 48] Parenthetically, the scholarly literature remains virtually silent on the impact of weight loss and emaciation on body image in the advanced cancer population.

In many instances a gap exists between abilities of patients and caregivers to come to terms and deal realistically with the consequences of anorexia. The former appear able to make a number of adaptations, which facilitate acceptance of appetite loss and its consequences, which caregivers cannot or will not make. Patients appear to experience greater social and emotional discord from this disparity than from any direct psychological effect of anorexia. Thus, although anorectic patients understand the long-term implications of insufficient caloric intake and generally make an effort to eat when they feel able to, they also come to accept or resign themselves to the ineluctable the limitations on their eating.[17, 37, 40]

It must be emphasised that, due to the paucity of studies that have specifically investigated the management of anorexia by patients with advanced malignant disease, the conclusions drawn from this review must be regarded as speculative. Research into the adaptations made by patients to compensate for appetite loss and its consequences should aid clinicians in the development of beneficial interventions, which, it is hoped, would aid both patients and caregivers struggling to cope with this common symptom in palliative care.

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Chapter 3: Manuscript 2 – Results Paper

Shifting to conscious control – psychosocial and dietary management of anorexia by patients with advanced cancer: Grounded theory interview study

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Introduction

Anorexia (literally, 'loss of desire') is one of the commonest symptoms experienced by patients receiving palliative care for advanced cancer[1-3] and is one of the most notoriously difficult to alleviate. Through its suppression of caloric intake, appetite loss is a major contributor to the malnutrition and emaciation characteristic of advanced cancer cachexia.[4] Severe depletion of physiological reserves of energy and protein are associated with asthenia, functional and immunological impairment as well as reduced life expectancy.[5] Anorexia is also known to have deleterious effects on the emotional wellbeing of patients and caregivers, and to strain familial relationships.[6-12]

Appetite stimulants are of limited use in the treatment of anorexia in the advanced cancer population. Synthetic progestins such as megestrol acetate effect orexia and increased intake in only a small sub-set of patients[13-15] and are of questionable use in very advanced disease.[5, 16] In the case of corticosteroids, appetite stimulation is rarely prolonged, tending to dissipate after three to six weeks.[14] Dietary counselling may be employed as an alternative treatment strategy; however, the most frequently recommended nutritional interventions attend to the problem of poor oral intake in isolation, i.e., patients are simply counselled to consume more calories and/or protein.[17] The need for psychosocial and educational interventions that assist patients in adjusting to anorexia has been identified by several researchers.[6, 10, 12]

Recent work has explored the manner in which family members of advanced cancer patients cope with their relatives' declining oral intake.[8, 9] At the moment, however, little is known about the strategies used by patients to manage anorexia. An understanding of these may guide clinicians to provide appropriate nutritional and psychosocial interventions which are currently lacking.

The purpose of this study was to discover the process that explains how patients with advanced cancer compensate for appetite loss and manage its emotional and social consequences.

Participants and methods

The procedures employed in this qualitative study were derived primarily from the principles of the Grounded Theory method associated with Glaser[18, 19] as well as a

number of practical aspects of data analysis articulated by Turner.[20-22] Following ethical clearance, we purposively sampled 12 patients with advanced cancer (defined as recurrent, metastatic or refractory) through a palliative homecare service and the outpatient department of a provincial cancer centre. After providing written informed consent, all participants were asked to complete a three-day dietary record to determine current intake.[23] Only those who self-reported anorexia, seven men and two women, were interviewed (Table 3.1). Based on their intakes of food, these participants were almost exclusively consuming insufficient levels of energy to maintain body weight[24-26]; however, none had ceased eating entirely. Recruitment continued until conceptual categories were well developed and theoretical saturation was obtained.

Data Collection and analysis

A total of 15 unstructured, audio-recorded interviews were conducted by JES. Participants were interviewed between one and three times. In order to provide some context to the discussion of their experiences with appetite, eating and weight changes, participants were first asked to describe the course of their disease trajectory. Issues relevant to the study objectives either surfaced in due course or were raised by the interviewer. Interviews were transcribed verbatim; errors, ambiguities and personally identifying information were then removed.

Data collection and analysis occured concurrently. The constant comparative method of qualitative analysis[19] was employed to code transcripts immediately following transcription. Categories of concepts were developed, saturated, abstracted, exploited and linked.[20] Ideas and hypotheses related to the developing theory (e.g., the properties of the emergent conceptual categories and their relationship to one another) were explored in later interviews. Preliminary analyses were developed and vetted through discussions at authors' meetings. Analysis was concluded when we identified the basic social psychological process that most comprehensively and parsimoniously integrated the major conceptual categories with sufficient explanatory power.[18]

The validity and reliability of our results were optimised by the use of a number of verification strategies from the inception of the study. These included

methodological coherence; appropriate sampling; concurrent data collection and analysis; theoretical thinking; and development of a comprehensive, consistent, parsimonious, and logical theory.[27]

Results

Anorexia and other symptomatic barriers to oral intake (e.g., food intolerances, altered chemosensory perception, nausea, xerostomia, constipation, dysphagia) severely neutralised participants' spontaneous, physiological desire for food. As a consequence, they were forced to abandon their reliance on this previously taken for granted impulse. To compensate, so that they could continue to eat, participants began to consciously drive their intake of food. The basic social psychological process of *shifting to conscious control* (over eating) was the fundamental adaptation that enabled participants to compensate for anorexia, if only temporarily, and manage its emotional and social consequences. *Shifting to conscious control* was comprised of four integrated stages: *recognising the changes*, *harnessing the motivation to eat*, *working within the limitations*, and *sustaining the shift*. Several of these stages were comprised of multiple phases or dimensions (Figure 3.1).

Stage I Recognising the changes

The process of *shifting to conscious control* was triggered when participants not only began to notice appetite loss and other barriers to oral intake, but recognised the threat posed by these changes. For participants who appeared to be suffering from primary anorexia (i.e., anorexia associated with dysfunction in the neurohormonal signalling pathways that regulate caloric intake),[28, 29] appetite loss began insidiously. When independent of other barriers to oral intake, anorexia was subtle, "creeping up."

> It just gradually started – you know, you'd miss meals, and you wouldn't eat breakfast, and you'd have very small suppers and small lunches, and things just didn't appeal to you. You know, you didn't really have an appetite.... [Participant 8]

A gradually declining appetite and the appearance of subtle, "flu-like" symptoms were often insufficient to elicit concern, however. Many participants did not realise the exceptionality and gravity of these changes until abnormal eating patterns,

cooking difficulties or unintentional weight loss had become extraordinary, persistent, or distressing.

On the other hand, participants with secondary anorexia (i.e., appetite loss and reduced intake secondary to other symptomatic barriers to oral intake)[30] emphasised the rapidity and intensity with which appetite was suppressed following anti-neoplastic therapy. For this group, appetite loss was usually immediate and overt. One participant stated: *"...after chemo for a few days...I would feel nauseous, and my whole body would just simply say, 'Eeeech, no way on that for food', and I just wouldn't."* [Participant 10] According to another, who suffered severe xerostomia whilst on a clinical trial:

> Yes, yes, the dry mouth and then the other symptoms there that I told you, that I just didn't feel hungry at all, eh? And how weird everything tasted. So I knew I must be losing weight, but I never thought it would be that bad.... [Participant 11]

Irrespective of the aetiology or rate of appetite loss, entry to the next stage of *shifting to conscious control* occurred when participants recognised that their declining appetites were somehow different from other temporary bouts of anorexia they had previous experienced. Within the context of a cancer diagnosis, such an realisation was invariably accompanied by the acknowledgement that injurious consequences of insufficient intake, such as weight loss, weakness, or death by starvation would ensue if they neglected to consciously stimulate eating.

> I'll starve to death. And I think it'd be easy [not to eat] and I kid you not, I maintain that's why cancer participants lose so much weight, is because food is not a pleasant—it's not. And I think that you have to be conscious of it, that if you don't eat, you ain't gonna survive very long. [Participant 9]

Stage II Harnessing the motivation to eat

Anorexia and other barriers to oral intake stripped eating of its rewarding characteristics. On balance, food was at best easily forgotten, and at worst repulsive, with few redeeming features to motivate participants to seek it; nevertheless, participants were resolute in their desire to maintain an adequate oral intake. They

employed reason and fear to stimulate eating when they were otherwise disinterested in or even actively repelled by food.

Recasting eating as a necessity

The belief that, as a result of having cancer, eating had become obligatory was pervasive amongst participants. The phrase "I have to eat" epitomised this motivational philosophy. The compulsion to eat was derived from the inescapable dependence of survival on the intake of food. Acquiescence to appetite loss was not an option that any of the participants considered, even though it was clear that it was often more pleasant not to eat. Several participants articulated that they could scarcely imagine themselves ever completely ceasing oral intake.

> It's a matter of survival: If I don't eat, I don't survive. That's the way I feel about it. It is a necessity. Even though you don't want it, it's something that must be taken. But I don't know if I would ever come to the point where I wouldn't eat anything. I don't think so, no. [Participant 12]

Although participants were cognisant that eating had always been a *sine qua non* of life, this knowledge had historically dwelt in the background of their minds and had exerted little influence on their drive to eat. In other words, whilst participants always knew that they 'had to eat', they rarely would have eaten because they felt compelled to in order not to become malnourished, but rather because they were hungry, or bored, felt socially obligated, etc. Their acknowledgement of the threat posed by a poor intake of food, within the context of a cancer diagnosis, caused the tacit understanding of the necessity of eating to be recast as a stark reality.

> Food is a necessary thing to fuel the body. It always was, but it was always pleasurable as well. Now it's just basically fuel. It's an extension of life, if you want to get really crazy about it. I mean, if I don't eat, I ain't gonna be around! [Participant 7]

Recasting eating as a necessity instilled in participants a powerful determination to carry on eating. This determination was so firmly integrated in participants' psyches that it was occasionally expressed axiomatically: "It's just doing it to do it,

just because I know I have to. It's not a problem, but I just don't have any desire to eat. But I'm eating, just to eat." [Participant 11]

Reframing the objectives of eating

Because of anorexia and other symptomatic barriers to oral intake, participants had little physical hunger and few cravings to satisfy; infrequently were they motivated to eat by spontaneous food ideation or the expectation of pleasure. The impulses that participants historically employed to drive the pursuit of food were either too severely weakened or infrequently experienced to be relied upon. Spurred on by the grave implications of prolonged, inadequate oral intake, participants reframed the objectives of eating around a number of putative, advantageous outcomes: slowing disease progression and deterioration, carrying on, maintaining or gaining weight, fighting cancer, keeping up strength and stamina, preserving quality of life and forestalling starvation. The achievement of these outcomes supported the determination to eat.

> When I dwell on it and study it and look at, quote, quality of life, unquote, I know I do have to eat, yes, because it's a clear factor on life expectancy if you allow yourself to deteriorate, which, by not eating, I know that there is as deterioration. [Participant 10]

When sufficiently motivated, participants quickly moved to implement the strategies that made eating possible.

Stage III Working around the limitations

Determined to carry on eating with little or no appetite, participants were faced with sorting out how they would manage a sufficient intake of food. In the third stage of *shifting to conscious control*, they attempted to override anorexia and other barriers to oral intake whilst limiting the evocation of physical distress from as a result.

Finding what works

As their eating capabilities began to erode, participants skipped meals, ate increasingly small servings, and generally attempted to eat when they had no spontaneous desire to do so; furthermore, they developed, tested, and implemented a wide variety of strategies to work around the impact of anorexia and other barriers to

oral intake on diet. Individual eating capabilities influenced the precise nature of the chosen intake strategies, which included taking nutritional supplementation, eating at specific times ("My breakfast… I have no problem eating my cereal. I don't know why. It seems to taste like it always did."), using time as a guide ("I look at the time and I think, 'Oh, I didn't have anything to eat yet.'"), having food brought to them ("But when it's put in front of me… I'm usually not too bad; I will usually get through most of it."), and watching others eat:

> If I let [partner] eat – cook her food and bring it in the living room and eat next to me, then the sight and the smell and the sound and that whole—what would you call it?—eating process would sort of spark my appetite a bit, eh? [Participant 3]

Drawing a line

Despite a strong resolve to eat and a repertoire of strategies to facilitate oral intake, participants periodically hit a proverbial symptomatic wall. This invariably triggered a state in which eating was felt to be temporarily impossible. In such situations participants' motivation to eat was effectively neutralised as they discontinued oral intake or refused to take any food whatsoever. Participants hit the wall when the sight, smell, taste, or mere thought of food provoked an intolerable physical distress or the conditioned expectation of one. Nausea and the anticipation of emesis (often associated with early satiety) were the terms most commonly used to describe these sensations, respectively.

> **P**: I don't even remember what it was we were eating at the time, but yes, I just thought, 'No, I just can't'—I think we were having salmon, and I just couldn't eat it, and salmon's one of my favourite foods. But I just didn't feel like I could just eat it at all.
>
> **JES**: Is that because if you did try to eat, it would make you nauseous?
>
> **P**: Yes, yes. Or feel like I was going to throw up. [Participant 11]

Nausea and the anticipation of nausea were interpreted symbolically by some participants as the active rejection of food by their bodies.

> Well, in the first place, the evening meal, I have a hard time to start. I'll eat very little, and I stop when I figure that—and my whole body's just rejecting it, just won't take it; that's all there's to it. [Participant 12]

Irrespective of a food's quality or its historical preference, the effort put in by others to prepare it, coercion by others to have it eaten, the desire of others to see it consumed, the level of motivation to eat, or any other factor, participants were categorical about their inability to eat after hitting the wall. In particular, the interaction between nausea and food was reported to cause an aversive reaction inimical to oral intake.

> [Son] used to set stuff before me—and I think, as I reflect on it, one of the big things was that I had no interest in eating. And unless you have suffered extreme nausea, you may not fully understand where I'm coming from there. Even when he was cooking, and we lived in a home at the time, and even when he was cooking in the kitchen, I had to go down to the basement; I couldn't stand the steam of the vegetables and that sort of stuff. Nausea is a terrible thing. [Participant 1]

Drawing a line represented participants' acknowledgement that they had reached the limit of their individual capabilities to motivate and effect eating and as such was the adaptive, cognitive response to hitting the wall. Although several participants indicated that their diminished oral intake evoked feelings of anxiety and distress in their caregivers, most of those interviewed had come to terms with the conflict between their determination to eat (believing that they "have to eat") and their inability to override nausea or the anticipation of emesis (feeling periodically that they "couldn't eat"). *Drawing a line* freed participants to execute the strategies that allowed them to manage the emotional and social consequences of declining oral intake and thereby sustain the shift to conscious control over eating.

Stage IV Sustaining the Shift

In order to support acceptance of anorexia, participants employed a number of concurrent strategies sustain conscious control over eating. One of their main effects was to facilitate greater acceptance of limited eating capabilities.

Going through the motions

Most participants were committed to putting in an effort to eat, even if it meant simply *going through the motions*. This helped to mitigate the social threat posed by anorexia and other barriers to oral intake. This strategy permitted those interviewed to join in the innumerable quotidian and special activities that involved food. One participant referred to partaking in family meals as creating a façade of normalcy around eating. This deflected emphasis away from his limited capabilities. *Going through the motions* generally helped participants to minimise the social disruptiveness of anorexia.

> Usually if you don't take something, everybody looks at you and says, "Well, is there something wrong with this food, or is he just not hungry?" As a matter of fact, sometimes that question is asked. But if I do eat something and they all are eating all right, that's fine with me. But it's never for their sake. It's because I'm at the table with them; I should eat something. If you went to a café with a group, well, naturally, they would expect you to have something if you were especially the one that invited them. [Participant 12]

> No, I go to wherever whenever I'm invited out or anything; I go. I eat what I can, and then I just have to leave the rest. People seem to understand that if you can't, you can't; just don't worry about it. [Participant 11]

Irrespective of the amount consumed, merely putting in an effort to eat was usually enough to validate participants' attempts to meet the reframed objectives of eating. *Going through the motions* allowed participants to maintain, at least ostensibly, an integral component of a normal life (i.e., eating). This contributed to the acceptance of anorexia. For some, it also aided the belief that they were maintaining the overarching fight against cancer.

Lowering expectations

Participants were generally realistic about their eating capabilities and expended little emotional energy grieving what they could no longer achieve. This equanimity was cultivated, in part, by *lowering expectations* – of themselves with respect to eating, as well as those held for the characteristics of food and meals. As with *going*

through the motions, *lowering expectations* allowed participants to salvage many of the non-nutritional benefits of eating. For example, those with lowered expectations could enjoy occasions that might have been difficult had the quantity or quality of food consumed been evaluated by prior expectations.

> I met some friends for lunch last week, and, you know, I had a bowl of soup. It was good, you know, whereas before you might have had a couple of beers and a burger or a chicken sandwich or something like that, whatever…But now just a bowl of soup, and I couldn't finish that, you know, so that was — but that doesn't matter; we still had, you know, the lunch time together… [Participant 8]

With lowered expectations, participants were able to divorce the quantity or quality of food consumed from the criteria used to valuate the act of eating or define a meal. This allowed them, and those around them, to interpret meagre or simple meals as being meaningful and more easily accept the limitations on their capabilities

Putting it into perspective

Few of the participants interviewed had any illusions about their prognosis. Despite the long-term implications of inadequate oral intake, the distant – and in many cases abstract – nature of these consequences ensured that they were overshadowed by more immediate concerns. Active symptoms such as pain and nausea could be extraordinarily physically distressing and psychologically all consuming. When participants considered the meaning of inadequate intake within the context of advanced cancer, they determined that it was by no means the most pressing issue facing them.

Monitoring changing capabilities

Because of the dynamic nature of anorexia and other barriers to oral intake, participants continually monitored what, when, and how much they could or could not eat. For a number of those interviewed appetite and/or other barriers to oral intake improved over the course of the study. As a consequence, these participants (temporarily) abandoned their efforts to come to terms with anorexia and instead attempted to establish a new set of intake strategies. Participants with significantly improved eating capabilities cycled back to *working around the limitations* until such

time as episodes of hitting the wall forced them to acknowledge their new limitations and re-draw a line.

Discussion

We employed the Grounded Theory method for several reasons. First, it promotes the creation of complex theoretical accounts that accurately represent the social situations under study.[22] Second, it facilitates the discovery of basic social psychological processes that people use to resolve common problematic situations.[18] The fundamental social psychological problem experienced by our participants was the conflict between their determination to eat and the struggle required to maintain an intake of food without an appetite. S*hifting to conscious control* was the adaptive process that compensated for anorexia and promoted the management of its emotional and social consequences.

Brief accounts of patient adaptation to appetite loss[6] and management of eating changes[12] have recently appeared; however, neither study elucidates the process employed or stages traversed by advanced cancer patients as they adapted to anorexia. Other work has outlined the coping strategies employed by family members,[8, 9] explored the meaning of intake cessation from the perspective of bereaved caregivers,[11] explicated the deleterious consequences of appetite loss on patient-family dynamics,[10] or described the experience of patients and family members in the period leading up to the introduction of home parenteral nutrition[7].

Participants experienced many of the same impediments to eating identified in other studies, such as nausea[7]; early satiety[6, 12]; loss of desire,[6] hunger,[12] or appetite[7]; food aversions[12]; dysphagia[7, 12]; and altered chemosensory perception.[6, 7] When asked, however, why these (mostly gastrointestinal) symptoms made them feel as if they were incapable of eating, nausea or the anticipation of emesis was consistently identified as the *ultimate* barrier.

When juxtaposed with the relevant extant literature on the experience of anorexia, our findings suggest that caregivers are far more willing and able to understand patients' reframed objectives of eating than their vacillating eating capabilities.[6-12] Caregivers who fight back against patients' declining intakes[8, 9] either cannot or

choose not to appreciate that the statement "I can't eat" is not the product of a rational choice; rather it represents patients' construction of reality.

When considered from the perspective of previous research on the trajectory of dying, the process of *shifting to conscious control* appears to be component of the larger conceptual category of "keeping going," which consists of two distinct elements: "trying to stay alive" and "creating a safety net."[31] "Trying to stay alive" resonates with the belief held by every participant we interviewed that they simply "had to eat." *Going through the motion* and *lowering expectations*, two dimensions of *sustaining the shift*, are congruent with the normalising activities and lifestyle modifications encompassed by "creating a safety net."[31] Additional research is needed that explores whether the strategies promoting acceptance of anorexia and limited eating capabilities truly normalise these changes or simply foster adjustment to their abnormal nature.[32]

We suspected that a fifth stage of *shifting to conscious control* existed, which accounted for the period in which patients could no longer work around the limitations on their eating capabilities. Despite our best efforts, we were unable to identify patients who had accepted that they could not eat,[12] and had thus ceased trying, and who were also cognitively intact and willing to be interviewed. Further research is required to modify the process[18] of *shifting to conscious control* so that it includes the portion of the disease trajectory leading to intake cessation.

Improving treatment

In this study, we have described the primary adaptations used by advanced cancer patients to manage anorexia. An understanding of the process of *shifting to conscious control* may improve clinicians ability to deliver appropriate and responsive interventions for this common symptom.[33] The participants interviewed in the present study, as those reported elsewhere,[1, 34, 35] retained the ability to eat with simple anorexia (i.e., appetite loss that is not aggravated by other distressing symptoms). This implies, first, that meticulous and proactive control of the many symptoms that interfere with eating, in particular nausea and delayed gastrointestinal motility (leading to early satiety and the anticipation of emesis[36]), may have a positive impact on intake of food.[7] Second, nutritional interventions ought to be tailored around the

protean eating capabilities of patients, with an emphasis on the avoidance of conditions and factors that provoke nausea or the anticipation of emesis. Third, clinicians must avoid reticence on issues related to appetite, eating and weight loss out of fear that treatment would be futile or that engaging patients on these issues might cause more problems than it solves.[12, 37]

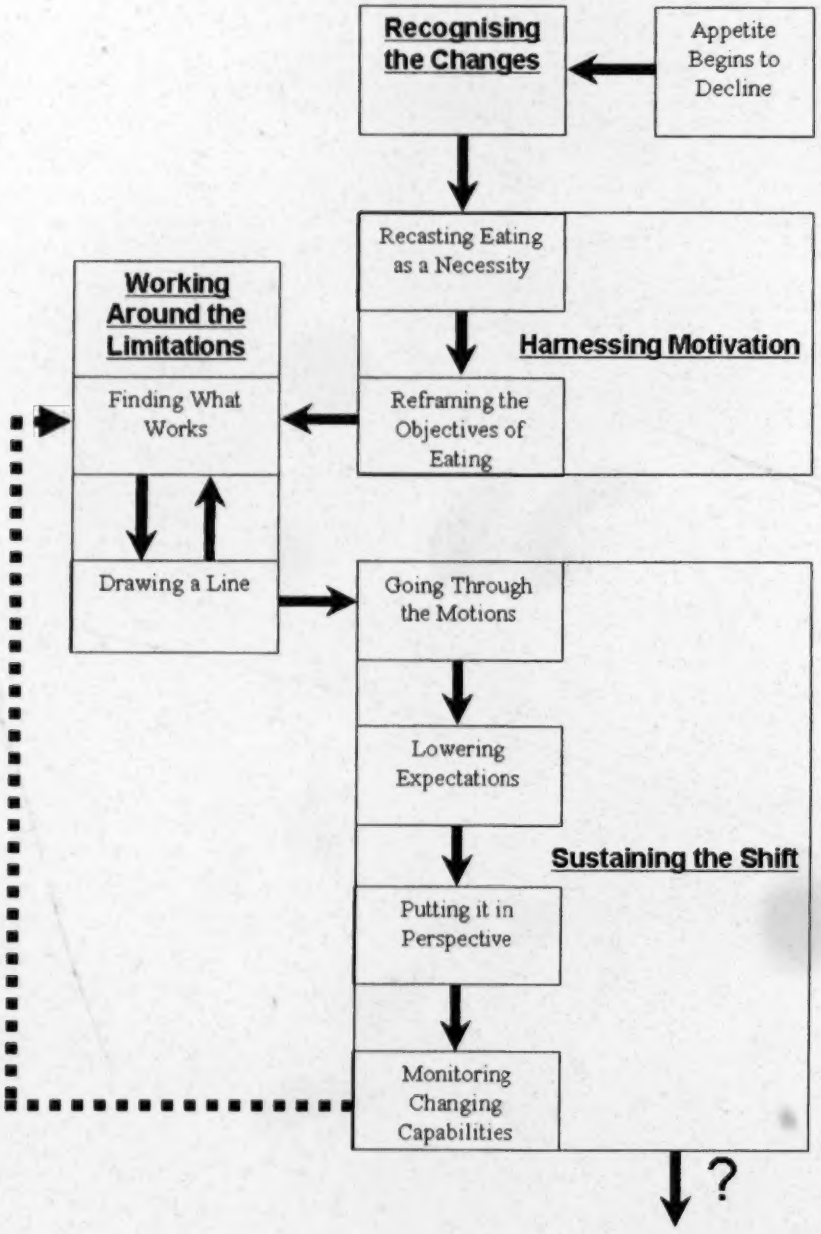
It has been suggested that advanced cancer patients and their family members/caregivers would be well served by interventions (e.g., through education or counselling) that promoted acceptance of anorexia and other eating changes.[6, 12] Our results suggest that participants readily accepted their limited eating capabilities if resisting them meant the provocation of emesis. In order to reduce conflict, caregivers must be counselled that d*rawing a line* is a cognitive response to what patients perceive is an involuntary act. Psychosocial interventions must, therefore, educate caregivers of the futility of pressuring patients to attempt food when they have hit the wall. Interventions should also foster an understanding in caregivers that patients go through the motions, lower their expectations and put anorexia in perspective in order to manage the emotional and social consequences of declining oral intake, and that these strategies cultivate acceptance. Caregivers must be encouraged not to sabotage, demean or otherwise interfere with these strategies.

Some caution must be exercised when applying our findings to the development of treatments for a general palliative care population. The process of *shifting to conscious control* was developed with a small, culturally homogenous sample of Canadian patients (all but one was white and of European descent); furthermore, all of our participants were still eating and thus were compensating for anorexia with varying degrees of success. Because of the social context in which these psychosocial interventions would be applied, they may not be as appropriate for patients from different cultural backgrounds and those who felt that eating was beyond their capabilities.

Table 3.1: Characteristics of nine advanced cancer patients interviewed

Characteristic	Median or Total	Range
Age (y)	**64**	46 – 83
Men (n)	**7**	
BMI (kg/m^2)	**22.6**	18.3 – 29.1
Weight loss from normal (kg)	**9**	0 – 21.4
Weight loss from normal (%)	**12.5**	24.5 – 0
Time to death from enrolment (weeks)	**22**	5 – 47
Primary site [*n*]		
Lung	**2**	
Gastrointestinal	**1**	
Haematological	**1**	
Prostate	**2**	
Melanoma	**1**	
Unknown or other	**2**	
Total energy (kcal/day)	**1862.8**	801.9 – 2199.1
Total energy (kcal/kg BW/day)	**28.2**	11.2 – 44.1

Figure 3.1: Stages and Phases of Shifting to Conscious Control



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Chapter 4: General Discussion

A Gap in the Literature

The purpose of this thesis project was to better understand the management of anorexia by patients with advanced cancer. The main impetus was the need for innovative therapies to treat this common, yet largely intractable symptom. We employed a qualitative research methodology (Grounded Theory) that permitted us to elucidate the basic social psychological process[1] (*shifting to conscious control*), used by patients to compensate for appetite loss and manage its attendant emotional and social problems. Ours is the first investigation to elucidate this process as well as the first to focus on the experience of anorexia primarily from the perspective of the patient rather than the caregiver,[2] family member[3, 4] or patient-caregiver dyad.[5-7]

The work presented here begins to fill an important gap in the scholarly literature. At the time this project was developed, only three previous investigations were available in which qualitative methods had been employed to analyse the experience of appetite loss and intake decline/cessation in an advanced cancer population.[2, 3, 4, 7] Whilst each these studies was (is) important and interesting in its own right, none examined anorexia primarily from the patient's perspective.

Meares[2] took a phenomenological approach to elucidate "the meaning of the gradual cessation of oral intake in adult in-home hospice patients with terminal cancer as described by women primary caregivers" (p. 1752). As her subjects were bereaved caregivers who had attended to patients, direct patient data was absent from her analysis. McClement et al.[3, 4] employed the grounded theory method to describe the responses of family members to the declining intake and weight loss of patients in hospice. This study represented the first comprehensive examination of the strategies used by family members to cope with the anorexia of patients. The authors reported that "doing what's best" was the basic social psychological process that governed family member' responses to this condition.[i] McClement et al. did integrate some information on the experience of patients in their analysis; however, this was but a minor component and focused on the manner in which patients were affected by the

[i] Unfortunately, neither the various stages and dimensions of this process (and the associated sub-processes of "fighting back", "letting nature take its course" and "waffling") nor their relationship amongst one another are ever explicated in print.

strategies employed by their relatives rather than their appetite loss itself.[ii] Holden's[7] work provided some clue as to how patients might adapt to anorexia. Beyond these citations, only anecdotal references to the deleterious impact of anorexia were available. For example, Dixon et al.,[8] described the frequent occurrence of a harmful "syndrome of psychosocial interactions" (p. 29) amongst patients and family members. The cycle that these authors portrayed begins as the patient's overall condition and his ability to tolerate food deteriorate. The family then

> becomes more desperate to prepare something acceptable. As each offering is refused, weary caregivers feel personally *rejected*, helpless, frustrated, and angry as one of the main avenues for expressing love and concern is thwarted. The dying person may attempt *to force-feed to avoid disappointing the family*, or may stop eating to force the family to accept the *reality* of the deterioration [emphasis added] (p. 29).

The familial tension evoked by meals and eating, related in part to the rejection alluded to in the preceding quotation, was detailed by Willans[9] in a short commentary in *Nursing Times*. Her observations resonate with both the preceding quotation as well as the results of exploratory research conducted nearly 25 years later.[6, 10] She wrote:

> Many families say loss of appetite and alteration in the patient's usual likes and dislikes, have caused tension while he was cared for at home. A wife feels she has failed when she has been unable to provide her husband with food that he fancied, and anxiety and frustration grow out of *rejected* meals [emphasis added] (p. 875).

Dornan[11] alluded to the guilt experienced by caregivers who come to feel, because of the patient's anorexia, "that they are not doing their best to maintain the patient in the best condition possible" (p. 38).

[ii] It is worth noting here that McClement et al. undertook their research in hospice. From the quotations provided in their articles, as well as personal communication with Susan McClement, it would appear that the patients interviewed were quite far along in their disease trajectory and most had ceased eating for all intents and purposes. Patients with these characteristics would likely be at the hypothetical fifth stage of the process described in Chapter 3.

Since this thesis project commenced, three additional papers have been added to the body of qualitative literature on the management of anorexia by advanced cancer patients.[5, 6, 10] The work by Souter[5] and Hopkinson and Corner[10] in particular have provided crucial new information about the adaptations and compensations made by patients (see Chapter 2). Yet, as with the previous work by Meares[2] and Holden,[7] they too fail to provide a coherent and thorough framework upon which clinical interventions could be built.[iii]

Management of Anorexia and the Development of Innovative Treatments

The overarching philosophy underpinning this thesis project was that innovative treatment strategies are required to aid advanced cancer patients to cope with anorexia; moreover, meaningful interventions must integrate the ways in which patients currently manage this symptom. To understand this rationale, one must appreciate that the therapeutic options currently available are very limited; therefore, in the absence of an ability to correct the basic physiologic problem, it appeared logical to consider ways in which clinicians could support the patient and family in adapting to anorexia.

Appetite loss, like cachexia,[12] is generally understood to be a poorly managed symptom.[iv] Little evidence exists to suggest that anorexia, declining intake or their psychosocial consequences are regularly treated in a proactive fashion by healthcare professionals – albeit, the proportion of patients who receive treatment for appetite loss is unknown.[13] Quite the reverse, appetite and weight loss may be viewed by many clinicians as taboo subjects/symptoms;[10] furthermore, caregivers have reported

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[iii] To be fair, Hopkinson and Corner[10] present a model of what they call the "Patient Experience of Living with Changing Eating Habits." This 'model', according to the authors, explains that patient concern over eating is evoked when "The reality of eating and the expectations of eating are… counterbalanced. To maintain balance and therefore not experience concern, patients respond to changes in reality and expectation. Patients respond to the challenge of expectation differing from reality on a continuum ranging from acceptance of the changes… to self action." It is somewhat difficult to see how this model provides as comprehensive a level of "understanding of the patient experience of living with eating difficulties" (as these two authors contend) as the theory of shifting to conscious control.

[iv] In a review of the pathophysiology of cancer anorexia, Laviano et al.[36] state "Cancer anorexia is a syndrome that can be effectively treated" (p. 692). The clinical research evidence they offer in support of this is somewhat thin and not supported by epidemiological data indicative of the number of patients who might be currently benefiting from these effective treatments. It would be ironic and tragic if effective treatments were available but, for what ever reasons, unused.

retrospectively that they were incredulous[3, 4] or unaware[2] that loss of appetite was a common and expected dimension of the dying process.

Standard interventions for cancer anorexia are of limited utility.[14] Although nutritional counselling may improve caloric intake in advanced cancer patients,[15] it does not increase appetite per se and by itself is unlikely to provide much of improvement in either quantity of quality of life – albeit, in a recently published study of cancer patients (both advanced and early stage) receiving radiation therapy, counselling was found also to increase objectively measured appetite and quality of life scores[16] Nutritional supplements appear to be tolerable; however, any augmentation of caloric intake is largely subverted by involuntary decreases in food intake at other meals of the day.[17] The pharmaceutical treatments most commonly prescribed for anorexia, progestins and corticosteroids,[13] have a number of drawbacks. The former are contraindicated for many patients[18] and produce meaningful results for only approximately one-third of those prescribed them.[19] The appetite stimulation seen with corticosteroids tends to dissipate after several weeks.[13, 20]

For a large proportion of anorectic patients, eating becomes ever more difficult as the malignancy progresses, and, at some stage of the disease trajectory, inappetence eventually becomes both total and irreversible. Dealing with the psychosocial consequences of this reality become an increasingly important factor in the provision of palliative care. For the purposes of determining the principal focus of anorexia interventions (i.e., whether the ought to be psychosocial or nutritional), there may be a need to distinguish between patients with an incurable malignancy and those who are very close to dying from one. Indeed, clinical practice guidelines for parenteral nutrition in palliative care depend on such a differentiation.[21] Bozzetti et al.,[22] assessed quantitatively measured quality of life (employing the Rotterdam Symptom Checklist) and survival in patients receiving home parenteral nutrition. These authors report that quality of life indices stabilised after once month's administration intravenous support and remained steady until approximately two months prior to death; additionally, nutritional status was maintained, although not restored to previously normal levels. Bozzetti et al. conclude, *inter alia*, a life expectancy of

greater than three months is required for malnourished, chronically obstructed patients to experience a stabilisation or improvement in quality of life.

At the moment, no guidelines exist that specify (based on objective criteria) the point in a patient's disease trajectory at which the improvement of psychosocial wellbeing ought to supersede that of nutritional status as the primary aim of anorexia treatment. Even if one were to take a three month life-expectancy as the inflection point (i.e., a completely aphagic person would likely starve to death in 60-75 days[22]) the inexactness of clinical prognostication would make this cut-off extremely difficult to implement effectively.

Despite the enhancement of nutritional status being the principal target of the commonest interventions, several authors suggest that improving psychosocial wellbeing ought to always take precedence. In a review article published several years after her study on caregiver perceptions of intake cessation, Meares[23] states that anorexia-cachexia has never been shown to be reversible or curable. Because of this, she admonishes clinicians to

> remember that treatment of cancer anorexia-cachexia syndrome is best directed at improving appetite and food intake only as they *relate to an improved quality of life.*[v] Not all palliative care patients with anorexia or weight loss should be treated and not all available treatments are appropriate [emphasis added] (p. 136).

This implication here is that an increased appetite is the most appropriate and effective means to improve quality of life for dying persons with anorexia. We are not convinced that it is.

If one were to assume that primary anorexia were fundamentally irreversible, it would seem clear that interventions ought to focus on assisting patients to live with this ineluctable symptom. And, in fact, this is the basic justification employed by Holden.[7] After commenting on the inability of megesterol acetate to provide a breakthrough in the treatment of appetite loss in palliative cancer care, she asserts that

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[v] We assume that Meares[23] uses the term "quality of life" akin to "subjective wellbeing[59]" (p. 753), which encompasses both physical and psychosocial elements, rather than as the score on a quantitative quality of life instrument.

"interventions will be most beneficial if oriented toward helping patients and families cope with the problem [anorexia] and its emotional ramifications" (p. 75). The same thinking lay at the heart of this thesis project.

This is not to say we repudiate the value of nutritional interventions to provide patients, especially those with less advanced disease, with increased physical functioning,[24-26] objectively measured quality of life[16, 17, 26, 27] or survival.[25, 27] Based, however, on the unlikelihood of dietary counselling alone to enhance these parameters,[13] as well as the poor efficacy of appetite stimulants, and the almost complete absence of useful advice for those patients for whom an improved nutritional status is either unrealistic or irrelevant, we chose to focus our efforts on building the foundations for new psychosocial interventions.

So why should we have examined the process by which patients compensated for appetite loss and managed its consequences? The data showing that most advanced cancer patients avoid distress[28] or anxiety[29] as a result of anorexia, the observation that they become resigned to eating problems,[7] and the lack of importance that hospice patients ascribe to lost appetite[3] all strongly indicated many patients do, in fact, cope with anorexia. In order not to proffer advice that was inimical to patients' natural coping strategies, it seemed logical to us appropriate and effective interventions ought to integrate these strategies, which were poorly recoded or understood as of early 2004. This belief resonated with – and indeed was influenced by – Poole and Froggatt's[30] conclusion that research into

> the meaning and problems associated with weight loss in patients with advanced cancer… is essential for the development of interventions that are appropriate and responsive to these problems, which thereby deliver benefits that are meaningful to patients and their families (p. 504).

Is Anorexia a Problem for Patients?

Another conclusion drawn by Poole and Froggatt[30] is that "certainly in the latter stages of disease, anorexia might be more problematic for carers than patients themselves, particularly within the home environment" (p. 504). Although these authors fail to define clearly what they mean by "problematic", based on their citation of Holden's[7] and Meares'[23] studies, Poole and Froggatt appear to be implying that

caregivers do not cope with anorexia as well as patients do. Whilst aspects of the work by McClement et al.[3, 4] appear to substantiate this theory, the other exploratory work published in the intervening years is largely ambiguous on this point.[5, 6, 10]

Irrespective of who finds anorexia more of a problem, patients or caregivers/family members, what is of more importance to the present thesis study is whether it is problematic for patients. Our results indicate that appetite loss is indeed a problem, but one that is managed well enough by most patients (in the context of advanced disease, and all the physical and psychosocial turmoil that accompanies it) to forestall distress. This finding may explain why only a minority of patients – albeit in only two studies – have been reported to experience distress or anxiety as a result of appetite loss. Hawkins[29] observed that only 36% of palliative cancer patients claimed to suffer anxiety due to this symptom, compared with 25% of patients in an earlier study by Addington-Hall and McCarthy.[28]

Cultural factors quite probably play a significant role in the ability of patients to cope with anorexia and avoid its deleterious social and psychological consequences. Oi-Ling et al.[31] surveyed 30 Chinese cancer patients in the last week of life and had them evaluate on a five point scale the distress they were experiencing from 13 symptoms, including anorexia. Ninety-three percent (93%) of patients reported some grade of distress due to anorexia, and 67% stated that they suffered grade three or four distress ("quite a bit" or "very much distressed"). These results compliment the 71% of Japanese family members who were "distressed" or "very distressed" by their relative's appetite loss in the last week of life.[32]

Ultimately, when one juxtaposes the findings of this project with those of Hawkins,[29] Addington-Hall and McCarthy[28] and Oi-Ling et al.,[31] one may reasonably conclude that objectively measured scores of anorexia-related distress may provide limited information on the experience of this symptom and its overall role in patient wellbeing. In particular, Asians and black West Indians[33] may suffer greater distress

than European or North American whites. Obviously, exploratory research is required to better understand the extent and nature of these inter-cultural differences.[vi]

***Shifting to Conscious Control* and the Regulation of Eating**

The participants interviewed for this thesis project expressed that having anorexia meant losing, to varying degree, the spontaneous drive to seek food. Cravings, incidences of food ideation and episodes of hunger (the physical sensation of needing food) became rare if they occurred at all. A number of concomitant symptoms, which we collective labelled barriers to oral intake, intensified the challenges of eating, and further eroded what little spontaneous desire for food participants had left. Symptomatic barriers to oral intake held the potential to make eating a miserable, distressing experience, which, through negative reinforcement, contributed to appetite loss.

The ability to at least partially override the passive and active components of anorexia (lack of desire and evocation of nausea by food, respectively) indicated that participants had abandoned their reliance on the spontaneous appetite. In its place, they substituted an intellectually generated motivation. That participants claimed to eat because they knew they "had to" indicated to us, *inter alia*, that they had become cognisant of the necessity to exert conscious control over their food intake, which we assumed their bodies had, for all intents and purposes, regulated for them in the past. The basic social psychological process *shifting to conscious control* was given its title because of participants' efforts to abandon reliance on the malfunctioning physiological mechanisms that regulated their intakes of food, and in their stead impose a purposive, cognitive process. The following quotation from one female participant well exemplifies the necessity of this shift:

> I'll starve to death. And I think it'd be easy [not to eat] and I kid you not, I maintain that's why cancer participants lose so much weight, is because food is not a pleasant—it's not. And I think that you have to be conscious of it, that if you don't eat, you ain't gonna survive very long.

[vi] The concluding sentence of Koffman et al.'s[33] paper states: "In addition, *qualitative research* should be conducted on why great symptom distress seems to develop more frequently in black Caribbean patients" [emphasis added] (p. 15)

The conceptual veracity of anorectic patients shifting from unconscious to conscious control over the initiation and maintenance of eating episodes is corroborated by research into a) the pathophysiology of anorexia and b) the regulation of food intake by the central nervous system. In healthy, weight-stable persons, the body is able to closely equilibrate energy intake and expenditure over time. A number of hormonal and neuropeptide signalling pathways which modulate intake play a crucial role in energy homeostasis.[34] For persons with anorexia, these pathways, become deranged such that the unconscious regulation of energy intake fails.[35-37]

We do not suggest, however, that eating is uninfluenced by non-physiological factors. In certain contexts, such as psychiatric disorders and dietary modification, reasoned behaviour and/or environment may moderate or even subordinate the role played by physiology. There can be little doubt that elements of eating, such as the precise selection of foods and the initiation of meals, although shaped by unconscious signals, are determined by cognitive processes. As Schwartz et al.[34] note, "Emotions, social factors, time of day, convenience and cost are but a few of the factors that are not biologically regulated, but nonetheless affect meal-to-meal energy intake" (p. 661). Levitsky[38] has gone so far to suggest that both adults and children "display very poor regulation of energy intake[39]" (p. 273) and "appear to be more responsive to the external environment than internal biological cues[40]" (p.623). In the context of dietary change, Pelletier et al.[41] rightly observe that "the decision to keep a healthier diet overrides the natural urge to derive sensory pleasure from indulging in decadent foods" (p. 247). Purposive restraint, first empirically documented by Herman and Mack,[42] also may be seen as conscious control substituting for physiological regulation of food intake in non-anorectic persons.[43] We are of the opinion, however, that, in healthy persons at least, ingestive behaviour, especially the drive to eat and the amount consumed, is governed more by the unconscious mechanisms of the central nervous system[34] than environmental or behavioural factors. As such, the basic social psychological process we identified perhaps would be more accurately referred to as a 'shifting from mostly unconscious to mostly conscious control'.

Blundell and Gillett[43] state that "Food intake (eating) is a form of behaviour that is subject to conscious control" (p. 263S). When considered in the context of our

findings, this proposition raises the question of whether our participants truly 'shifted' to conscious control over a behaviour (eating) that was already under such cognitive regulation. We cannot overemphasise that a conscious effort was required to overcome the passive disinterest in food caused by anorexia. The more inappetence was exacerbated by symptomatic barriers to oral intake, the more will and determination was required to continue eating. All but one participant we interviewed articulated that there was an upper limit to the distress they would endure in order to eat. They recounted times at which they could not eat under any circumstances. We referred to these episodes as 'hitting the wall', which represented the resumption of control over eating by unconscious mechanisms. It is unclear whether the signals to terminate eating reported by our participants (nausea of the anticipation of emesis; see 4.6 below) would be conceptualised appropriately as elements of the 'regulation' of food intake by the central nervous system. Hopkinson and Corner,[10] however, propose that for patients to "*live with eating changes was to trust one's body to be self-regulatory, as before illness*" (p. 13)

Similar to the arguments presented above regarding the roles of behavioural regulation and choice in control of food intake, one could assert that participants made a conscious decision to cease eating when they could no longer tolerate the distress provoked by it. In other words, when participants described not being abole to eat what they really meant was they were unwilling to do what it took to maintain intake. Such an argument seems to us as fatuitous as one stating that a starving man would 'choose' to eat if food were put in front of him. There would appear to be certain evolved signals, such as hunger and nausea, that, when of sufficient intensity, cause people to act in an ostensibly involuntary manner, which may be potentially antagonistic to their rationally generated desires. In this thesis project, participants strongly desired to maintain an oral intake, but utterly refused to so when distressed by nausea; however, even repeated thwarting did not appear to have much of an impact on the resolve to carry on eating, an observation which is likely related to the social psychological imperative to eat common amongst the dying in Western – albeit, not necessarily Eastern[44] – cultures (see Chapter 2).

We could not help but notice the resonance between the difficulties faced our anorectic participants to maintain an intake of food and Blundell and Gillett's[43] stark appraisal of efforts by healthy persons to consciously control their eating in order to manage or lose weight:

> The attempt to exercise volitional self-control over a form of behavior strongly determined by both physiological dispositions (probably with a genetic base) and environmental pressures is often self-defeating and may lead to a disorderly pattern of eating or a serious distortion of the structure of behavior (p. 268S).

It would appear, then, that effective and sustained conscious control over eating is quite challenging with and without an appetite.

***Recognising the Changes* and Vigilance**

For our participants, simply experiencing declining appetite and other barriers to oral intake was not enough to trigger the shift to conscious control. They had to recognise that their declining appetites were somehow different from other temporary bouts of anorexia they had previous experienced. More important, they had to acknowledge that their declining intakes of food were not transient and probably not going to improve anytime soon. This second criterion is critical. It is unlikely that participants' conviction that they had to eat would have been as common or compelling had they known that their appetites would going to return before they became too malnourished. *Shifting to conscious control* thus began when participants acknowledged that the self-evident, injurious outcomes of insufficient intake, such as weight loss, weakness, physical deterioration or death by starvation would rapidly ensue if they did not exert conscious control over their eating. To put it another way, the recognition that dire consequences would attend if they chose simply to acquiesce to the lack of physiological desire for food – to not bother expending the energy required to undertake a difficult and at times physically distressing activity – was the cognitive act that initiated *shifting to conscious control*.

This property of the conceptual category, *qua* basic social psychological process stage, *recognising the changes* is illustrated by one participant who was completely

put off food by nausea after undergoing a Whipple procedure. In the period following his surgery, he had been ambivalent towards eating and accepted that he could not do so. His resistance to resuming an oral intake of food (he was enterally fed for weeks following his major surgery) provoked conflict with his adult son, who admonished him that he would die unless he began to eat. Yet, the particpant said,

> I didn't care. My attitude was sort of, 'So be it.' I was so nauseated. I mean, I didn't care to the point where I wished to die or anything like that; *I didn't imagine I was going to die.* [laughs] But I had a kangaroo bag, and they were feeding me all this stuff in it, and that was satisfying me all right [emphasis added]

Because he recognised that his anorexia and lack of oral intake were not likely going to lead to his death, he did not feel the compulsion to begin immediately *harnessing the motivation to eat*. Whilst he recognised the changes in his eating, he declined to acknowledge that they urgently threatened his health. As such, he did not employ the process of *shifting to conscious control* to compensate for anorexia.

In her grounded theory study of women who had a hysterectomy, Chassé[45] identified *experiencing the symptoms* and *perceiving a health problem* as the initial two phases of *experiencing a disruption*, the first stage of the basic social psychological process *establishing the boundaries of normality*. These first phases are collectively quite similar to *recognising changes*, the first phase of *shifting to conscious control*. For the women in Chassé's investigation "the realisation that they were ill was the factor that forced the informants to explore their symptoms systematically in order to identify their *boundaries of normality* [emphasis in the original]" (p. 98).[45] In the case of this thesis project, all but one of the participants in this was aware of his/her cancer diagnosis at the onset of anorexia; accordingly, most experienced appetite loss in the context of an incurable and progressive disease. In addition, most participants predicted that weakness and physical deterioration would result from prolonged episodes of grossly insufficient intake. Compared to the women interviewed by Chassé, then, our participants did not have the time to undertake other preliminary strategies (e.g., 'learning to read the body", "evaluating the illness

experience" [45]) before taking positive action to compensate for appetite loss manage its emotional and social consequences appetite loss.

Norris,[46] Wilson[47] and Siegl and Morse[48] all describe the concept of 'suspecting' health-related changes or problems with health as the first stage or phase of a basic social psychological process related to illness. In all of these instances, however, the suspecting was done by a relative of the ill[47, 48] or pregnant[48] person. In addition, these suspecting periods seemed to last substantially longer than the recognition stage of *shifting to conscious control*. For example, Wilson[47] interviewed husbands whose wives received chemotherapy. In order to suss out the aetiology of the suspected health threat facing their wives, they first became aware, then worried and finally began to act before 'finding out' the cancer diagnosis.[vii] All these phases took time to navigate, a luxury not afforded our participants under the threat of starvation. Even our participants for whom (primary) anorexia was unrelated to anti-neoplastic therapy did not appear to suffer appetite loss for long before initiating the compensatory process. On the contrary, those who experienced anorexia following treatment quickly acknowledged the threat and acted immediately. That all but one of our participants knew he/she had cancer, if not an incurable disease, at the time appetite began to fail likely contributed to the urgency and intensity with which the motivation to eat was harnessed.

The concept 'suspecting' described above was first categorised by Morse and Johnson[49] as belonging to the first stage of the 'illness-constellation model', entitled the 'stage of uncertainty'. Morse[50] later extended this framework, and suspecting was absorbed into the category 'vigilance'. Morse's description has only limited concordance with *recognising changes*. ('Vigilance' is a stage in a formal theory about acute or chronic illness and injury and as such its level of abstraction renders it quite distant from the experience of a symptom such as anorexia.) Nevertheless, her discussion of the role of maintaining control in precipitating compensatory action resonates with or description of *shifting to conscious control*: "loss of control is perceived to result in the loss of the person's ability to monitor and direct care, loss of

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[vii] As a side note, Wilson used "recognizing changes" as the title of one the phases in her theory. In her work, however, this conceptual category describes, *inter alia*, the emotional and life changes that husbands experienced *after* their wives completed chemotherapy.

awareness, and ultimately *loss of self* [emphasis added]." For the participants we interviewed, uncompensated appetite loss was a grave threat to "integrity of self[50]". As its title suggests, *shifting to conscious control* facilitated the restoration of some control over an essential component of life: eating.

***Working Around the Limitations* and the Ultimate Barrier to Oral Intake**

One of the unique and potentially more controversial findings of this thesis project is the observation that nausea (whether chronic or provoked by food) or the anticipation of emesis appeared to be, in the majority of instances, the *ultimate* barrier to oral intake for participants. When asked why, despite having resolved that they had to eat, participants could not make themselves do so, time and time again the proffered answer was that they felt nauseous or anticipated emesis. So whilst xerostomia, constipation and taste and smell alterations or aversions were all unpleasant in and of themselves, they could be overridden as long they did not provoke nausea when eating was attempted or considered (for some the mere thought of food could provoke nausea). Needless to say, participants who suffered bouts of nausea independent of the interaction between food and other symptoms (e.g., chronic nausea following chemotherapy) rarely could eat much.

Because of the natural antipathy most humans have towards the sensation of nausea, episodes of hitting the wall triggered a psychological coping response that we called *drawing a line*. The act of *drawing a line* was the initial and most important strategy used by participants to accept that the factors motivating them to eat were no match for their desire not to be physically sick as nausea. Thus, when forced to 'choose' between anxiety related to a meagre intake of food (attendant to hitting the wall) and the active physical suffering caused by nausea, participants were quite content to take the former if it meant that the later would abate. In our opinion, the ineluctability of this choice is the primary reason why advanced cancer patients are reported in previous research to have accepted[5] or become resigned to anorexia,[7] or placed less importance on this symptom than others.[3]

When participants said that they could not eat, it emerged that what they really meant was that they were repelled by nausea or the conditioned anticipation of emesis. Similar to nausea, the feeling of fullness served as a very powerfully barrier

to continued oral intake. One female participant who experienced early satiety (a condition associated with either delayed gastric emptying or distorted physiological regulation of satiety) visited a seafood restaurant with her family. She had so looked forward to the meal that she avoided eating the entire day just make sure she had enough of an appetite to tackle the crustacean. After consuming the claws, but before moving on to the tail, she felt full and ceased eating. When the interviewer asked why she had to stop, this is what she said:

> I was enjoying that lobster so much, I could not make myself eat it because I might be sick, and I would not, no; I'd throw it in the garbage before I'd finish it, eh? because I—no. As much as I like something, I will *draw the line*. No, I won't [emphasis added]

Then a short while later she added:

> No, I don't—no. I know that I've got to eat. That's the bottom line. But to say, if I had to force myself—it's sort of like if I were to force myself to eat any more lobster—which I was enjoying; it just broke my heart that I just went to put a forkful in my mouth, and I just got it halfway there, and it just, 'Oh, I can't do this.' I just couldn't do it.

To understand the challenge of continuing of eating when one is truly full, (i.e., the force exerted by the body's evolved satiety mechanisms), the reader is commended to the documentary film *Super Size Me*. In one scene, the filmmaker, Morgan Spurlock attempts to consume a super sized McDonalds Double Quarter Pounder with Cheese Extra Value Meal® (approximately 1560 kcal, 65 g fat, 33 g trans + saturated fat).[51] As he makes his way through this Brobdingnagian meal, he begins to suffer palpable physical distress. The discomfort that he experiences becomes ever more intense as he desperately attempts to swallow the last bites of burger and the remaining few fries lingering at the bottom of the vast sleeve in which they were served. Moments after finally completing this nauseating task, he promptly leans out the open window of his SUV and vomits lavishly on the pavement.

The sufferance of similar distress may occasionally be attempted by cancer patients for a suitably compelling reason; however, similar end results may be

accurately predicted. For example, McClement et al.[3] report the case of an anorectic hospice patient who ate in the presence of her husband only to vomit immediately after his departure – "he hadn't reached the elevator yet, and she was throwing it all back up" (p. 97). Several participants interviewed for this thesis project acknowledged that the self-defeating nature of force feeding themselves was a reason they shunned this behaviour.

Hopkinson and Corner[10] list a number of changes experienced by their sample of patients, which interfered with eating, including loss of hunger/enjoyment, food aversions, and early satiety. According to Orrevall at al.,[6] patients named "a variety of factors including nausea, loss of appetite, weakness, swallowing difficulties, gastrointestinal dysfunction, and the changes in the small and taste food" (p. 1282) as leading to the inability to eat. In a similar manner, Souter,[5] who describes anorexia as a "fickle phenomenon", notes that the variation in patients' eating capabilities often "appeared inexplicable, while at other times it was related to factors such as pain, nausea, bloating, constipation, smells and size of portion" (p. 527). She later identifies early satiety, taste and smell alterations and lack of desire as the ultimate causes of incidences of eating cessation. Her account shares much in common with the experience of participants who shifted to conscious control.

> Patients tried hard to fight and not give in to the cancer, often forcing food down. Despite their desire to eat more they were unable to do so however hard they tried: *'I just can't' was said with great finality and strength of feeling.*[viii] For two [sic] it as related to early satiety, bust taste changes and lack of desire also appeared to play a part [emphasis added] (p. 529-30).

As noted above, whilst the participants interviewed for our study did experience these three symptoms, they did not appear to directly trigger intake cessation, i.e., without being mediated by nausea or the anticipation of emesis. We observed that simple loss of desire could be overridden, whilst taste and smell alterations (and most other symptomatic barriers to oral intake) were only decisive when they interacted with food to provoke nausea. Only when satiety was intense enough to lead to the

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[viii] The last participant we interview, an elderly man with cancer of the prostate made this point more cogently than any other: "if you can't take it, you can't take it; that's all there is to it."

anticipation of emesis did our participants refer to it as a factor that immediately precipitated the cessation of eating. Souter's[5] findings are somewhat at odds with ours, in part we suspect, because she does not appear to have asked the same question we did regarding the proximal cause of intake cessation, i.e., what's really stopping you from eating?[ix] Although nausea and the anticipation of emesis were by far the commonest answers to this question (either in so many words or clearly implied), in a few incidences pain was identified as another decisive factor. What nausea, vomiting and pain have in common is that they are very active and potentially debilitating symptoms.[52] Simple loss of desire, in contrast, is not an active symptom. Taste and smell alterations, for example, although active and therefore likely to reduce appetite, are not pervasive; furthermore, whilst they may be disturbing or bothersome, chemosensory changes do not appear to cause physical distress per se beyond nausea. Further research is clearly needed to test whether the role played by nausea and the anticipation of emesis in intake cessation is a vital as we propose. If so, meticulous control of the symptoms that precipitate them would represent a potential target for anti-anorexia interventions in palliative care.

***Sustaining the Shift* and Normalisation**

Knaft and Deatrick,[53] analysed the concept of normalisation in the context of family responses to the illness or disability of a member. The authors suggest that this nebulous process applies to a given familial situation when the members:

> 1. Acknowledge the existence of the impairment. 2. Define their family life as essentially normal. 3. Define the social consequences of their situation as minimal. 4. Engage in behaviors designed to demonstrate the essential normalcy of their family to others (p. 219).

In the final stage of *shifting to conscious control*, participants employed several – often coincident – strategies that had the side-effect of helping them accept the limitations on their eating capabilities. The normalising activities identified by Olson et al.[54] in their study of dying trajectories ("creating a safety net" (p. 298)), resonated

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[ix] The following question was actually posed by JES: "So really, what's stopping you—if you say to someone or to me, 'I cannot eat'?"

well with *going through the motions* and *lowering expectations*. When we compared these dimensions of *sustaining the shift* against Knaft and Deatrick's[53] criteria for normalisation, we similarly found quite good correspondence. All of our participants acknowledged the limitations on their ability to eat normally. Few expressed that their family lives had been disrupted by anorexia and most failed to report adverse social consequences because of it – in our framework because of the impact of *drawing a line*, *going through the motions* and *lowering expectations*. Knaft and Deatrick's final criterion, the engaging of "behaviors designed to demonstrate the essential normalcy of their family to others", does not apply especially well to the experience of advanced cancer patients with anorexia; however, based on our interview data, it would appear, for some participants at least, that one of the purposes of *going through the motions* was to maintain a sense of normalcy. As one said

> I do prefer to sit down with Mother and my brother and sitting at the same table, and even though they're enjoying their food and I'm not, I won't darken their whole day by saying, "Oh, this is crud and crap" and everything else. And when they say, "How's it going?" you say, "Oh, fine." And yes, just part of more normal—

On the other hand, this participant also referred to eating socially as allowing him "to maintain that façade of normalcy". This implies that *going through the motions* comprised an element of disingenuousness, which allowed participants to dissemble their true feelings about their limited appetite and eating capabilities. One of Holden's[7] informants explained that she would sit at the table too tired or weak to eat, but liking "*to act like things are normal*" (p. 78). The participant who actually used the phrase *going through the motions* to describe his behaviour averred that it was equivalent to "pretending to eat"; however, this man also insisted that he was fine with *going through the motions* if it contributed to a positive social experience.

> Usually if you don't take something, everybody looks at you and says, "Well, is there something wrong with this food, or is he just not hungry?" As a matter of fact, sometimes that question is asked. But if I do eat something and they're all are eating all right, that's fine with me. But it's never for their sake. It's

> because I'm at the table with them; I should eat something. If you went to a café with a group, well, naturally, they would expect you to have something if you were especially the one that invited them.

Others who commented on this strategy also appeared to perceive *going through the motions* not as a smokescreen or a means to an end but an activity that was genuinely engaged in because of the social benefits obtained from it.

We do not have enough relevant data to determine unequivocally whether the strategies participants employed to manage the social and emotional consequences of anorexia (to sustain the shift) were perceived by them as normalising their limited appetite and eating capabilities. It may be that these strategies simply allowed them to adjust to the abnormal nature of their situation rather than properly normalise it.[53] Recently published work of Orrevall et al.,[55] who explored the experience of advanced cancer patients on home parenteral nutrition (HPN), suggests that some form of normalisation around anorexia and its dietary consequences does occur. "These patients appear to adjust responses to their 'normal' situation as chronically ill, with limited food intake and limited physical activity, rather than using their pre-sickness state as the norm" (p. 968). The question of the normalisation of anorexia and attendant limitations on eating capabilities requires further investigation.

If we are equivocal as to whether the dimensions of *sustaining the shift* allowed our participants to normalise their limited eating capabilities, we are more certain that these strategies cultivated the acceptance that started with *drawing a line*. *Going through the motions* and *lowering expectations* collectively facilitated the maintenance of eating as a social activity. This effect, along with the general psychological impact of *putting it in perspective*, made the emotional and social consequences of anorexia easier to manage, and therefore accept. *Drawing a line* may be seen as fostering acceptance because participants felt that they were powerless to resist nausea and the anticipation of emesis. The putative causal relationship between hitting the wall and acceptance is alluded to by Souter,[5] who writes that "reluctant acceptance of their own limitations meant that patients were not distressed constantly by their loss of appetite, [because] they knew they were doing all they could [emphasis added]" (p. 530).

When considered from the perspective of previous work, *going through the motions, lowering expectations* and *putting it into perspective* may be seen as facilitating acceptance by allowing participants to adapt to the consequences of anorexia. In her study of men and women who had survived a myocardial infarction, Johnson[56] identified "accepting limitations" as a strategy employed as part of the final stage of "living again". The similarities between the dimensions of *sustaining the shift* and "accepting the limitations" are quite striking.

> Often the informants would change their expectations in order to incorporate their new limitations into their lives. By *decreasing or changing their expectations* the informants eliminated their sense of limitation. The informants accomplished this by reexamining their goals and expectations and by *reconsidering their priorities*.... Ultimately [limitations] were considered a part of living [emphasis added] (p. 80).

The participants in this thesis project never "eliminated their sense of limitation", because periodic episodes of hitting the wall served to constantly remind them of the ultimate limitations of their resolve to eat. Nevertheless, it seems clear that *lowering expectations* and *putting it into perspective* are basic strategies used by ill or recovering persons to manage their limitations through acceptance.

Future Directions I: Measuring Quality of Life Related to Anorexia

Even the most studied anorexia-cachexia therapies have little demonstrable effect on quality of life. Is this a matter of fact? Is one or more important element of quality of life not included in the measurement tools? Are the tools themselves too crude to detect subtle but meaningful changes after therapeutic administration? These questions are important because of the value of an accurate, legitimate, easily administered evaluation of psychosocial wellbeing *qua* quality of life.

Jatoi et al.[19] reviewed 15 separate studies (most involving advanced cancer patients) on the effect of megestrol acetate on global quality of life scores. They report the administration of megace had little impact on this endpoint. Nevertheless, Jatoi et al.[19] conclude, notwithstanding, that it is reasonable for oncologists to prescribe it. They suggest that the quantitative tools typically used to assess the

impact of megace on global quality of life may be either insensitive or fundamentally inappropriate for the task. The implication is that patients do experience psychosocial benefits from improved appetite (via orexigenic drugs), but these are going undetected by the tools used to measure global quality of life.

Barber et al.[57] note the "tools available for the study of nutrition-related quality of life issues are at present somewhat blunt" (p. 281). Indeed, it is difficult to accept that such instruments are sensitive enough to give researchers the quality and quantity of information that is required to understand such a complex phenomenon. Even the Functional Assessment of Anorexia/Cachexia Therapy (FAACT) Subscale, a subjective assessment tool specifically developed to gauge the impact on quality of life of appetite, satiety, food selection, eating patterns and changes in body mass,[58] does not "directly tackle the social impact of weight loss or anorexia, relying upon sensitivity of the generic social well-being subscale to detect such difficulties[30]" (p. 504). It is disquieting that more researchers do not heed the caveat issued by Cohen et al.[59] that "Interpretation of quality of life results should, however, consider the limitations of current instruments [emphasis added]" (p. 754). Jatoi et al.[19] also note

> It might not be surprising that successful treatment of anorexia does little to influence favorably overall quality of life, if other symptoms are viewed as stepping forward as the severity of anorexia takes a step back.... [O]verall quality of life might not improve with megestrol acetate because relief of anorexia would amount to nothing more than a shifting of symptomatology in the setting of advanced cancer. Hence, patients benefit from appetite improvement, but global quality of life remains unchanged (p. 2932).

To the best of our knowledge, no study has examined the lived experience of advanced cancer patients who were prescribed an appetite stimulant; accordingly, the type and degree of benefit conferred by improved appetite – albeit, not necessarily increased intake – on patient wellbeing is unknown. (The deleterious effects of unpleasant side effects are similarly opaque.) Orrevall et al.[55] support the use of qualitative methods to reveal the impact of nutritional treatment modalities on psychosocial wellbeing/quality of life. At the end of the day, when one considers the middling efficacy of orexigenic drugs and their possible side effects, exploratory

research seems absolutely necessary to test Jatoi et al.'s[19] conclusion that appetite is "important in its own right – independent of global of quality of life, independent of survival, and independent of any other clinical end point" (p. 2932).

Future Directions II: Psychosocial Interventions

The findings of this thesis project include several salient departures from the extant literature on the experience of anorexia in advanced cancer. One of the most significant is our choice to exclude caregiver reports from the data collected. Indeed, ours is the first study to examine this issue solely from the perspective of the patient. We chose this research strategy because we felt it would increase the likelihood of us discovering and accurately explaining the basic social psychological process by which patients compensated for loss of appetite and cope with its consequences. As noted above (p. 52), innovative treatments to help patients better manage anorexia (the development of which was the overriding justification for this project) must, for obvious reasons, integrate the management strategies that they already employ.

Somewhat ironically, despite our exclusion of caregivers, most of the recommendations for improving psychosocial interventions outlined in Chapter 3 are concerned with helping caregivers better understand and accept patients' anorexia. Advanced cancer patients generally appear to compensate for anorexia to the best of their inherent capacities by harnessing motivation; they then manage its emotional and social consequences through acceptance. In other words, patients seem to possess a fairly strong, natural ability to cope with appetite loss – albeit, this capacity certainly lies along a spectrum and is likely a function of a number of factors including personality type and culture. Based on the foregoing, the source of patients' emotional and social distress logically must be assumed to have a large extrinsic component, i.e., it emanates from caregivers, family members and/or other persons. This conclusion is supported, both implicitly and explicitly, by the extant literature.[2, 3, 4, 5, 6, 7, 10]

In addition to the other areas of further research identified earlier in this and Chapter 3, we believe that the recommendations for psychosocial interventions directed at caregivers must be developed into proper treatment strategies, which would then require evaluation. Before this should happen, the issue of the proportion

of caregivers who exacerbate the problematic nature of anorexia for patients must be addressed. For example, in Holden's[7] sample of 14 patient-caregiver dyads, four patients "reported their caregivers tried too hard and this had become a source of conflict" (p. 81). Hopkinson et al.[10] report that tension around food and eating was acknowledged by 10 of 30 families. According to Souter,[5] whilst only one caregiver (of seven) exerted pressure on the patient to eat, four of the latter "said that their greatest concern regarding loss of appetite was the worry it caused their carers" (p. 527). Because of reluctance on the part of caregivers to exacerbate patients' worries around food, the former internalised their feelings which "inevitably took a toll on the carer' health" (p. 528). Souter concludes that anorexia caused relational strife in a minority of cases; however, her own findings indicate that deleterious emotional and social consequences may occur because of internalised as well as open discord. The extent of conflict attendant to appetite loss and limited eating capabilities merits investigation, as does the nature of any common familial characteristics that might predict it.

Our results suggest that a lack of empathy on the part of caregivers is partially responsible for their unwillingness or inability to understand both the validity of patient claims that they cannot eat as well as the strategies used by them to cultivate acceptance of anorexia. Research is required that establishes the reasons why this lack of empathy exists, and why it is evident in only some caregivers. A basic understanding of the psychological state of caregivers who fight back against their relatives' anorexia[3, 4] would help determine the psychosocial approaches that would have the greatest likelihood of effecting acceptance and decreasing conflict.

Several deficiencies in this thesis project also warrant remediation through further research. First, our small sample size and its high level of cultural homogeneity somewhat decrease the generality of our findings. It would be interesting to see how advanced cancer patients from non-European cultural backgrounds adapt to anorexia and manage its emotional and social consequences. In addition, unlike some of those interviewed by Hopkinson et al.,[10] none of participants had accepted that they could not eat (rather than merely accepting the limitations of their capabilities). Whether such patients had ever compensated for anorexia and then quit, or whether they

simply lost their appetites and refused to harness the motivation required to maintain an intake of food is unclear. Regardless, our inability to include the experiences of those patients who do not employ the basic psychosocial process of *shifting to conscious control* generally limits the applicability of our findings to the portion of the disease trajectory that lies closest to death (sometimes referred to nebulously as end-stage or very advanced disease). As much of the conflict around declining intake appears to occur in the latter stages of cancer as eating becomes more and more challenging,[3, 4] an understanding of how patients closer to death manage anorexia and intake cessation should increase the specificity of psychosocial interventions.

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